A New Tomorrow



At NCBDDD, we long to see the day when:

Every child is born with the best health possible.

We can define the causes of and prevent blood disorders and their complications.

We can explain why some children have birth defects and developmental disabilities and others do not, and we can prevent those conditions.

All people with disabilities live healthy, productive lives.

In order to create this new tomorrow, there are imperatives before us today. Together, we can make advancements by addressing our targeted priorities:

- Assuring child health through prevention, screening, and early identification.
- Improving the health of people with disabilities by addressing risk factors for chronic conditions and infections.
- Preventing deep vein thrombosis and bleeding disorders in women.

We have to make the issues of birth defects, developmental disabilities, disability and health, and blood disorders forefront in the national public health agenda. These conditions, many of which are treatable and/or preventable, are costing people their lives, taxing the health care system, and keeping many from living life to the fullest.

Investing in surveillance and epidemiology research is critical to understanding prevalence, risk factors, and the efficacy of our interventions. With current dialogue about health reform, we have a unique opportunity to not only raise visibility of these issues but also to facilitate advancement for the millions of people impacted daily by these conditions.

We extend our sincere thanks and gratitude for the collaboration and efforts of our Friends of NCBDDD (formerly the External Partners Group, EPG). A coalition of government and private sector participants, Friends of NCBDDD works to enhance the mission and activities of NCBDDD. For more information about the group or how to join, please visit www.friendsofncbddd.org.

Our world-renowned scientists will continue breaking ground with research to identify causes and risk factors of conditions like deep vein thrombosis, autism, and cerebral palsy. We will continue working with communities and partners to create programs and interventions that help children and adults get the services they need. We will continue health education and outreach to ensure all persons living with a disability or blood disorder are able to live healthy lives.

But, we cannot do it alone.

It will take support from researchers, non-profit organizations, health care professional associations, policymakers, educators, consumers, and more to make this day a reality. To realize our vision of a new tomorrow, we must continue to dream passionately, hope faithfully, and strive diligently. While we are sure to face challenges – and even some setbacks – on our journey, we can look forward to celebrating our successes together.

NCBDDD Organizational and Financial Landscape

The National Center on Birth Defects and Developmental Disabilities was established by the Children's Health Act of 2000. Our center is organized into three divisions, which are focused on human development and disability, birth defects and developmental disabilities, and blood disorders. Our center is comprised of some **400 dedicated professionals working** within multidisciplinary teams.

NCBDDD Organizational Chart Science and National Center Health Communication Public Health Team Science Office on Birth Defects and Resource Management Developmental Disabilities Office Policy, Planning, Office of the Director Program Development and Evaluation Team Division of Birth Defects and Division of Human Development Division of Blood Disorders and Disability **Developmental Disabilities** Early Hearing Detection and Intervention (EHDI) Laboratory Team Pediatric Genetics Team Disability and Health Epidemiology and Ťeam Surveillance Team Child Development Prevention Research Team Studies Team Informatics Team Birth Defects Developmental Prevention Research Disabilities Branch Branch Branch Prevention Research Surveillance Team Surveillance Team Team Fetal Alcohol Syndrome **Epidemiology Team Epidemiology Team** Prevention Team Learn the Signs. Act Early. Team

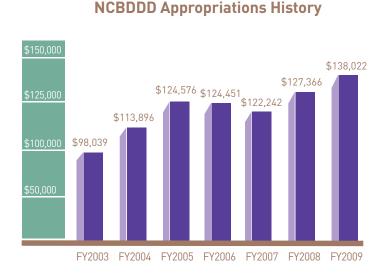
Below you will find information about our fiscal year 2009 budget as well as information about our budget trend since we began operations in April 2001.

Autism 14.78%

Fetal Alcohol 7.33%

Folic Acid

Infant Health



Diamond Blackfan Anemia .37% Hemochromatosis .24% Thalassemia 1.35% Birth Defects 15.30% Spina Biffida 3.96% ADHD 1.27% Fragile X 1.38% Special Olympics 4.00% Reeve Paralysis Research Center 4.15% Muscular Dystrophy 4.55% Tourette Syndrome

Limb Loss 2.10%

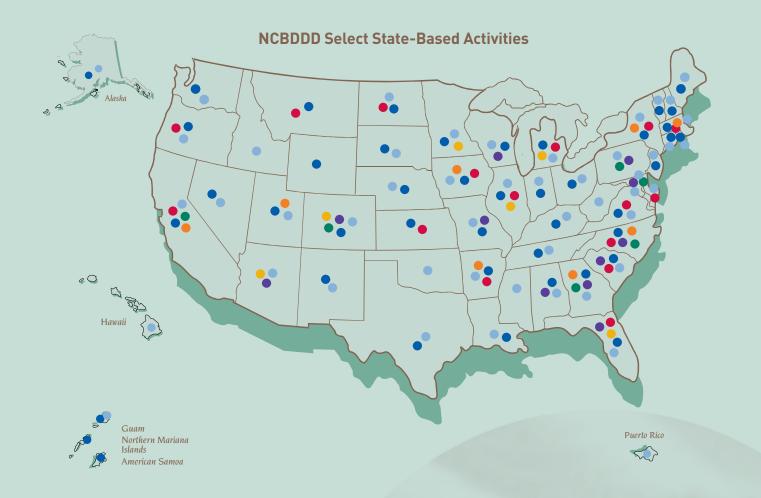
Disability and Health

NCBDDD Budget Authority FY 2009: \$138.02m

> Early Hearing Detection and Intervention 7.87%

A Picture of NCBDDD's Reach

The surveillance and research we conduct at NCBDDD impact the lives of people throughout the United States. Thanks to our collaborative global initiatives, we are also touching lives in many other countries. Below is a map of some of our domestic surveillance and research activities.



- Autism and Developmental Disabilities Monitoring Network (ADDM)
- Birth Defects Monitoring and Tracking Centers
- Centers for Birth Defects Research and Prevention (CBDRP)
- Disability and Health
- Early Hearing Detection and Intervention (EHDI)
- Hemophilia Treatment Center (134 HTCs nationwide, 1 or more HTC per represented state)
- Study to Explore Early Development (SEED)

Notable 2009 NCBDDD Scientific Publications

Each year, our scientists contribute to the development of numerous publications and articles demonstrating our commitment to advancing science. Below is a list of **key** publications that demonstrate the scientific scope of our work in 2009:

- Alcohol use among pregnant and nonpregnant women of childbearing age – United States, 1991-2005. MMWR Morbidity and Mortality Weekly Report. 2009; 58(19):529-532.
- Armour BS, Ouyang L, Grosse SD, Campbell VA, Thibadeau J, Joseph D. Hospitalization for urinary tract infections as a signal of the quality of preventive health care received by people with spina bifida. Disability and Health Journal. 2009; 2(3):145-152.
- Arneson CL, Durkin MS, Benedict RE, Kirby RS, Yeargin-Allsopp M, Van Naarden Braun K, et al. Prevalence of cerebral palsy: Autism and Developmental Disabilities Monitoring Network, three sites, United States, 2004. Disability and Health Journal 2. 2009; 45-48.
- Ashrani AA, Key NS, Soucie JM, Duffy N, Forsyth A, Geraghty
 S. Septic arthritis in males with haemophilia. Haemophilia. 2008; 14:494-503
- Austin H, Lally C, Benson JM, Whitsett C, Hooper WC, Key NS. Hormonal contraception, sickle cell trait, and risk for venous thromboembolism among African American women. American Journal of Obstetrics and Gynecology. 2009; 6:e1-e3.
- Bertrand J. Interventions for children with fetal alcohol spectrum disorders (FASDs): Overview of findings for five innovative research projects. Research in Developmental Disabilities. 2009; 30(5):986-1006.
- Biernath K, Holstrum W June, Eichwald J. Hearing screening for newborns: the midwife's role in Early Hearing Detection and Intervention. *Journal of Midwifery and Women's Health*. 2009; 54(1):18-26.
- Boulet SL, Boyle CA, Schieve LA (209) Health Care Use and Health and Functional Impact of Developmental Disabilities Among U.S. Children, 1997-2005. Archives of Pediatric and Adolescent Medicine. 2009; 163(1):19-26.
- Campbell VA, Gilyard JA, Sinclair L, Sternberg T & Kailes
 JI. Preparing for and responding to pandemic influenza:
 implications for people with disabilities. American Journal of
 Public Health. October 2009; 99 Suppl 2:S294-300.
- Centers for Disease Control and Prevention. Prevalence of diagnosed Tourette Syndrome in persons aged 6-17 years – United States, 2007. MMWR Morbidity and Mortality Weekly Report. 2009; 58(21):581-585.
- Centers for Disease Control and Prevention. Prevalence of Duchenne/Becker muscular dystrophy among males aged 5-24 years – four states, 2007. MMWR Morbidity and Mortality Weekly Report. 2009; 58(40):1119-1122.

- de Willige SU, Pyle ME, Vos HL, de Visser MC, Lally C, Dowling NF, Hooper WC, Bertina RM, Austin H. Fibrinogen gamma gene 3'-end polymorphisms and risk of venous thromboembolism in the African-American and Caucasian population. *Journal of Thrombosis and Haemostasis*. 2009; 101:1078-84.
- Duke CW, Correa A, Romitti PA, Martin J, Kirby RS. Challenges and priorities for surveillance of stillbirths: A report on two workshops. *Public Health Reports*. 2009; 124(5):652-659.
- Gilboa SM, Correa A, Botto LD, Rasmussen SA, Waller DK, Hobbs CA, et al. Association between pre-pregnancy body mass index and congenital heart defects. American Journal of Obstetrics and Gynecology. 2010; Jan. 202(1):51.e151.e10. Epub 2009 Sept.
- Grosse SD, Krueger KV, Mvundura M. Economic productivity by age and sex: 2007 estimates for the United States. *Medical Care*. 2009; 47(7 Suppl 1):S94-S103.
- Grosse SD, McBride CM, Evans JP, Khoury MJ. Personal utility and genomic information: Look before you leap. Genetics in Medicine. 2009; 11(8):575-576.
- Grosse SD, Lollar DJ, Campbell VA, Shamie M. Disability and Disability-Adjusted Life Years: not the same. Public Health Reports. 2009; 124(2):197-202.
- Grosse SD, Schechter MS, Kulkarni R, Lloyd-Puryear MA, Strickland B, Trevathan E. Models of comprehensive, multidisciplinary care for individuals in the United States with genetic disorders. *Pediatrics*. 2009; 123(1):407–412.
- Hamner JC, Mulinare J, Cogswell ME, Flores AL, Boyle CA, Prue CE, et al. Predicted contribution of folic acid fortification of corn masa flour to the usual folic acid intake for the US population: National Health and Nutrition Examination Survey 2001-2004. American Journal of Clinical Nutrition. 2009; 89(1):305-315.
- Holstrum WJ, Biernath K, McKay S, Ross DS. Mild and unilateral hearing loss: implications for early intervention.
 Infants and Young Children. 2009; 22(3):177-187.
- Hvidtjorn D, Schieve L, Schendel D, Jacobsson B, Svaerke C, Thorsen P. Cerebral Palsy, Autism Spectrum Disorders, and Developmental Delay in Children Born after Assisted Conception: A Systematic Review and Meta-analysis. Archives of Pediatric and Adolescent Medicine. 2009; 163(1):72-83.
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 abnormal laboratory haemostasis: a prospective crossover
 study of intranasal desmopressin and oral tranexamic acid.
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- Kulkarni R, Soucie JM, Lusher J, et al. Sites of initial bleeding episodes, mode of delivery and age of diagnosis in babies with haemophilia diagnosed before the age of 2 years: a report from the Centers for Disease Control and Prevention's (CDC) Universal Data Collection (UDC) project. Haemophilia. 2009 Nov; 15(6):1281-90.
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- Surveillance for pediatric deaths associated with 2009 pandemic influenza A (H1N1) virus infection – United States, April–August 2009. MMWR Morbidity and Mortality Weekly Report. 2009; 58(34):941-947.
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